YOUR KIDNEY

Connection

Spring 2019

The overwhelming theme from our consultations was the need for more support. You, the kidney community, expressed the emotional and financial toll of kidney disease on patients, carers and families. And access to quality care is a major issue affecting those living in regional and remote parts of the country.

The enthusiasm of the kidney community in responding to the development of the Action Plan and the generosity of patients and families in sharing their stories has been remarkable. We believe the Action Plan is a genuine reflection of your concerns and we hope that it marks the beginning of lasting changes to kidney health in Australia.

We are full steam ahead into planning our largest community event of the year, the Big Red Kidney Walk on Sunday 8 September. We thank you for your enthusiastic support of all our events, and the team and I look forward to seeing you at one of the five flagship walks, or hearing about your fantastic efforts at a community walk. Let’s all step out in red together!

Thanks,

Chris Forbes
CEO Kidney Health Australia

Spring is shaping up to be a busy and exciting time for us. We submitted the National Strategic Action Plan for Kidney Disease to the Commonwealth Government and we look forward to its release so we can move forward with its recommendations.

We have successfully wrapped up our Kidney Kids Camp and the Kidney Kar Rally 2019. Thank you to all the participants who got involved and revved up their communities and friends to donate.

Chris Forbes
CEO Kidney Health Australia

4 September
Polycystic Kidney Disease (PKD) Awareness Day
8 September
Big Red Kidney Walk
14 November
World Diabetes Day

2019 CALENDAR
OF EVENTS

BIG RED KIDNEY BUS
2019/20 CALENDAR

VIC
Mildura
Monday 29 July – Saturday 7 September 2019

Warrnambool
Monday 4 November – Saturday 14 December 2019

Lakes Entrance
Monday 13 January – Saturday 22 February 2020

Melbourne
Monday 2 March – Saturday 28 March 2020

Ballarat
Monday 6 April – Saturday 2 May 2020

NSW
Port Macquarie
Monday 2 September – Saturday 19 October 2019

Nelson Bay
Monday 28 October – Saturday 14 December 2019

Sydney
Monday 6 January – Friday 24 January 2020

Batemans Bay
Monday 3 February – Saturday 14 March 2020

Umina Beach
Monday 30 March – Saturday 9 May 2020

Subscribe to our monthly e-newsletter at kidney.org.au/subscribe
The 2019 Big Red Kidney Walk on Sunday 8 September is already shaping up to be the biggest one yet so get red-y to show your support for people living with kidney disease.

There is not much time left!
Each year participants descend in a sea of red across our five flagship walks in Brisbane, Melbourne, Sydney, Adelaide and Perth. There is something for everyone, with activities for the kids, live music and entertainment, as well as prizes for top fundraisers and best dressed.

Our kidney community take their preparation very seriously, going to great lengths to source red themed costumes. So start sifting through your wardrobe!

At the time of going to print, we have over 2,000 people registered to walk with us on the day, they have also already raised over $170,000 to help people living with kidney disease. There is still time to get involved so we encourage you to rally your friends, family and co-workers to sign up at www.bigredkidneywalk.org.au or even simply donate.

If you can’t make one of our flagship walks, you could take a leaf out of the Fraser Coast Kidney Club and hold your own. Our Fraser Coast Kidney Club completed their Community Walk in May and raised an amazing $1,300. They are already revving up for next year’s Walk!

Visit bigredkidneywalk.org.au to find out more!
N E W S

**BIG THANK YOU TO MELBOURNE ICE**

For over 10 years, Therese has been supporting the valuable work of Kidney Health Australia through entering our K Lottery. It was never a goal of hers to win K Lottery, the lottery was simply a timely reminder to carry on her support for a worthy cause.

The first prize in our National Lottery was $100k of gold, so you can imagine it was quite a shock for Therese when she was informed about this “absolutely life-changing” win.

From all of us at Kidney Health Australia, congratulations Therese and thank you for your support over the last decade!

**If you want a “life-changing” experience like Therese, then enter our Winter Warmer K Lottery and become our next K Lottery winner.**

Enter the lottery at [kidney.org.au/lottery](http://kidney.org.au/lottery)

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**KIDNEY HEALTH AUSTRALIA RESEARCH AWARDS**

**13 AUGUST 2019**

Last year Kidney Health Australia relaunched its medical research program, presenting $250,000 in grants.

We are happy to share with you that we were again able to award an additional $250,000 in grants in 2019/2020. We will be seeking applications for Research Stream 2 - Making kidney transplants last longer.

Kidney Health Australia Research will prioritise research in three areas:

- Basic science
- Psychosocial
- Clinical science/population health.

Full information regarding the application process and dates will be available on the Kidney Health Australia website in September.

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**MELBOURNE ICE**

Big thank you to Melbourne Ice for giving our kidney families free tickets to the Melbourne Ice vs Canberra Brave game on Sunday 28 July.

Although Melbourne Ice put up a great fight, they were defeated by Canberra Brave 7 – 2, however this loss didn’t dampen the spirits of our Kidney families who were thrilled to have a day out.

In support of Kidney Health Australia, our Kidney Kid, Tyler dropped the ceremonial first puck to mark the start of the game.
Congratulations and THANK YOU to all the Kidney Kar Rally participants for raising more than $440,000 to help support Kidney Kids and youth programs, like the Annual Kidney Kids Camp.

Huge thanks also for all the hard work and commitment from Rally Director, John Paine and wife Maree who organised the 31st rally from Port Macquarie to Armidale via Capricorn Coast.

The winner of this year’s Kidney Kar Rally was Kar 201 – Bone Crusher, driven by Brett and Don.

Followed by Kar 2 - The Aristocrats, driven by Angus and Rodney and Kar 73 – Rusty Racing, driven by Michael and David.

The top three fundraisers were Team Xplant, raising $66,202, The Artline Team, raising $40,500 and K & K, raising $33,452.

Xplant driver, John has been participating in the rally for the last 10 years and this year he celebrated his 10th anniversary of his kidney transplant. He was fortunate to receive a kidney from his wife.

Special thanks to event ambassador Supercar driver Chaz Mostert and thank you to Biante Model Cars for making this possible. Chaz was such a great sport and even tried his hand at rally driving, swapping his Ford Mustang GT for a rally car.

While it was great to see the rally cars manoeuvre the dirt roads, our Rallytives took a break from the roads at the rodeo in Rockhampton. It was definitely a highlight of the week and gave everyone a small break before completing the last half of the rally.

10 cars have already secured their spot for next year’s rally. If you’d like to join our next rally or would like more information, phone Rosina Cardakija on 0481 908 218 or email kidneykarrally@kidney.org.au to receive an information pack.
On Thursday 30 May, 113 children aged from 8 - 17 years, including siblings descended on Lord Somers Camp on the Mornington Peninsula for four fun-filled days of team based activity.

The special session kicked off with a cricket workshop by former Australian cricketer and our ambassador, David Hussey, along with Rob, Simon and Alistair from Cricket Victoria – South East Country. We are also really fortunate to have, recently appointed Coach of the Melbourne Stars and Cricket Victoria, David Hussey, MC the Melbourne Big Red Kidney Walk.

From the sheer energy and excitement of the kids on day one, it was no surprise that they thoroughly enjoyed themselves and had a very emotional last night together.

While the kids are safely back with their parents, we continue to receive touching comments/stories from the kids expressing that they no longer feel alone now that they have met other children like them.

Kidney Kids Camp gives children living with kidney disease the opportunity to enjoy a camp experience which they are generally denied because of the nature of their illness. It also offers the opportunity to meet kids in the same conditions and for parents it removes the stress that comes with managing chronic kidney disease, even if it is just for four days.

We are able to offer this invaluable program to families at no charge due to the fantastic fundraising efforts of programs such as the Kidney Kar Rally.
It’s wonderful you are thinking about donation, we know it can be very daunting! Receiving a kidney transplant can be life transforming and living donors are a much needed source of kidney transplants.

Potential living kidney donors are thoroughly assessed for any health issues that might be relevant to their future kidney function with only one kidney and those with chronic illnesses will unlikely be accepted as donors. Successful living donors may be eligible for the Supporting Living Organ Donor Program.

In general, people can donate a kidney to a loved one safely and it is possible to live normal lives with just one kidney. Some people are even born with one kidney. After a kidney is removed, the remaining kidney grows in size and takes on the workload of both kidneys and kidney function can remain stable.

It is important to continue to look after your kidneys, especially post-transplant. This includes adopting a healthy lifestyle and regular check-ups with a GP. Some transplant units also follow up on live donors regularly.

Talk to your local transplant team about the risks and benefits of kidney donation and how your kidney will be assessed for potential donation. Ask as many questions as you like, as often as you like. You should be certain you are making the right decision for yourself and your potential recipient.

We have some fantastic resources to help you learn more about your kidneys, life with one kidney, and living donation on our website, kidney.org.au

To learn more about Kidney Transplants, you can access Kidney Health Australia’s range of resources at www.kidney.org.au/ your-kidneys/ support-kidney-transplant including:

- An Introduction to Kidney Transplantation booklet
- An Introduction to Kidney Donation by Living Donors booklet
- My Kidneys My Choice Decision Aid
- Kidney Helpline 1800 454 363

Dr Shilpa Jesudason MBBS, FRACP, PhD is a clinical and academic nephrologist specialising in obstetric nephrology, general nephrology and transplantation, and Clinical Director at Kidney Health Australia.
Glenis was 33 when she was formally diagnosed with nephritis. Seriously ill and given just nine months to live, she was just five months on the wait list when she received the life changing news that she would undergo a kidney transplant.

Glenis has always regarded her transplant as a special gift that required all her care and attention, keeping herself healthy and well, for herself and her growing family.

“Right at the very beginning, I thought if I ever got a kidney transplant I’d look after it, and I’ve kept to my promise,” Glenis said. “I can’t believe I keep achieving these milestones and I don’t think my family can either, but they are very happy and supportive.”

Glenis’s granddaughter even donated to Kidney Health Australia in lieu of giving wedding favours to guests at her wedding earlier in the year. Glenis’s husband Bill is particularly pleased that Glenis has been able to enjoy a long and happy family life with their three daughters, six grandchildren and seven great grandchildren.

“He’s as happy as Larry, you’d think it was his (kidney),” Glenis said.

Glenis’s doctor, Dr Helen Rhodes said Glenis’s anniversary was a remarkable achievement that had enabled her to live a full life.

“Glenis is very lucky to have received such a wonderful gift, that she has treasured and looked after for 50 years” says Dr Rhodes.

In 1994, Theresa’s husband Dom was diagnosed with kidney disease and given a 10 year life expectancy. In order to extend his life, Theresa donated one of her kidneys to her husband.

Since then they have been long-time supporters of Kidney Health Australia and have generously decided to leave a gift in their Will to Kidney Health Australia. As bequestors, Theresa and Dom join a special group of people who are committed to ensuring a brighter future for people affected by kidney disease.

Theresa has made fundraising a way of life, creating a ‘swear jar’ with a penalty fee of $2 or $5. In celebration of their 22nd anniversary of the kidney transplant, on 17 March 2020, Theresa will donate the money to Kidney Health Australia.

Thanks Theresa for your dedication to the cause and we look forward to seeing how much is raised or rather, how much swearing has gone on in your household!

If you would like further information about leaving a gift in your Will to Kidney Health Australia, please contact Bequest Officer, Roberta Armitage on 03 9674 4383 or roberta.armitage@kidney.org.au
CREATING SPECIAL FAMILY MEMORIES WITH THE BIG RED KIDNEY BUS!

Our Big Red Kidney Bus makes it possible for families to holiday together and create special memories to last a lifetime. For Noel, after a year of dialysis treatment at the Coburg renal unit, his special memory came in the form of a surprise family holiday at Lakes Entrance, thanks to the efforts of his daughter Nicolina, the renal unit and the Big Red Kidney Bus team.

After Nicolina spotted information about the Bus at the renal unit, she was inspired to plan the surprise family holiday at Lakes Entrance for Noel and her siblings. Beautiful gestures such as this make the bus an invaluable asset and with summer approaching, it’s a good time to soak up the sun in some of the best parts of the country! We have spots remaining in Nelson Bay, Mildura and Warrnambool for 2019.

Or if you are thinking about celebrating the New Year in a new location, we have plenty of availability for 2020 in Sydney, Batemans Bay, Lakes Entrances and Melbourne, see dates on front.

For more information or to book your seat on the bus please visit kidney.org.au/bus

BROOME WAS THE LATEST STOP ON THE ‘YARNING KIDNEYS’ CONSULTATION JOURNEY, TO UNDERSTAND THE NEEDS OF ABORIGINAL AND TORRES STRAIT ISLANDERS COMMUNITY MEMBERS LIVING WITH KIDNEY DISEASE, DIABETES OR WHO HAVE HAD A KIDNEY TRANSPLANT.

So far 125 community members have shared their kidney journey and collectively identified priorities to inform the new KHA-CARI (Kidney Health Australia – Caring for Renal Impairment) Guidelines for the management of chronic kidney disease (CKD) for Aboriginal and Torres Strait Islander peoples.

Feedback so far suggest the new guidelines should be comprehensive and include management of lifestyle risk factors, prevention, early detection and treatment options, and should involve community members in the development and implementation process. All agreed that kidney health had not been given the funding and priority it required to improve indigenous kidney health outcomes.

The ‘Yarning Kidneys’ consultations complement the Catching Some Air Project conducted by Dr Jaqui Hughes in Darwin, Alice Springs and Thursday Island.

For more information on the consultations, visit www.kidney.org.au